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## **Assessing gross motor function, functional skills, and caregiver assistance in children with cerebral palsy (CP) and cerebral visual impairment (CVI)**

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*Document Version*

Publisher's PDF, also known as Version of record

*Publication date:*

2016

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Salavati, A. (2016). *Assessing gross motor function, functional skills, and caregiver assistance in children with cerebral palsy (CP) and cerebral visual impairment (CVI)*. [Thesis fully internal (DIV), University of Groningen]. Rijksuniversiteit Groningen.

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## **Summary and general discussion**



## Summary and general discussion

The overarching aim of this dissertation was to contribute to the recognition and understanding of the presence of CVI in children with CP and, as a result, to adequate care and support for these children. Being aware of the extent that CVI affects a child with CP at the level of gross motor function, functional skills, and caregiver assistance is important in order to support these children and their parents. This thesis focused especially on: (1) whether and to what degree gross motor function, functional skills, and caregiver assistance in children with CP and CVI differ from those with CP and without CVI; (2) the development of an adapted version of the PEDI-NL and GMFM-88 for children with CP and CVI and determining their reliability; and (3) the development of two CVI Motor Questionnaires (CVI-MQs) for children with CP and determining their validity and usability.

### General/principal findings

The initial purpose of this study was to determine whether and to what degree the level of gross motor function and functional skills in children with CP and CVI as well as caregiver assistance were different in comparison with the corresponding group of children experiencing CP without CVI. Therefore, the data aggregated from 23 children experiencing CP with CVI were compared with data from 23 children with CP without CVI matched for GMFCS, mental development, and age at testing. Scores for GMFM-88 and the PEDI-NL were employed to compare the level of gross motor function, functional skills, and caregiver assistance between both groups. The results indicated that self-care, mobility, and social functioning in the group of children with CP with CVI were significantly more affected than in the matched group with CP and without CVI and that this difference can be explained by the presence of CVI. Also, children with CP with CVI achieved obvious lower scores in all dimensions of gross motor function including laying and rolling, sitting, crawling and kneeling, standing, walking, running and jumping when compared with children with CP without CVI.

Children with CP and CVI have an inherent problem with proper identification and processing of visual information. Functioning of these children can be quantified with the PEDI-NL and the GMFM-88.

However, the original PEDI-NL and GMFM-88 do not take visual functioning into account. Therefore, the results on these tests most likely do not reflect the actual motor capacity and underestimate the potential functioning of these children.<sup>1,2,3,4,5,6</sup> In order to measure motor skills and functional skills in children with CP and CVI, the verbal support/instruction, manual support, types of equipment, and environment of the content of PEDI-NL and the GMFM-88 were adapted. These adapted versions appeared to be valid and reliable. These adapted versions are additional supplements available for professionals. Prior to using these supplements, professionals must first be familiar with the original instructions of the PEDI-NL and the GMFM-88.

After determining the reliability of the adapted version of GMFM-88 for children with CP and CVI, research was focused on whether the adapted version of the GMFM-88 for children with CP and CVI resulted in higher scores and was a better reflection of their gross motor function per se without the influence of impaired visual abilities. Therefore, the scores of the original and adapted GMFM-88 were compared in the same group of children with CP and CVI. The comparison between the scores on the original and adapted GMFM-88 in children with CP and CVI yielded higher or similar scores in all dimensions of gross motor function including lying, rolling, sitting, crawling, kneeling, standing, walking, and running. The adapted GMFM-88 provided a better estimate of gross motor function per se in children with CP and CVI that was not adversely affected by their visual problems. On the basis of these findings, we recommend using the adapted GMFM-88 to measure gross motor functioning in children with CP and CVI. Paediatric physical therapists and occupational therapists using the adapted versions of the PEDI and GMFM-88 could determine a better estimation of functional ability and motor functioning of the child with CP and CVI. As a consequence, the approach and treatment of the child with CP and CVI will improve which may contribute to improved self-esteem and development of these children. Thus, e.g., during treatment, the therapist should give a child with CP and CVI more time to respond to a stimulus and should use extensive verbal instruction and manual support to help the child accomplish a task. Furthermore, a familiar environment can result in the

successful performance of daily skills, in contrast to an unknown or less familiar environment. To that aim, it is important to use the adapted PEDI-NL and GMFM-88 in the same environment and the same condition to evaluate a child's level of functioning.

Children with CP who may be labeled as “noncompliant”, “oppositional”, or “clumsy” could also be suffering from unidentified CVI. Early identification of CVI could lead to an emphasis on the correct determinants and proper focus of the comprehensive treatment which helps children in their development. A motor screening tool consisting of items related to the contribution of visual perception to perform a motor activity may be beneficial to paediatric physical therapists and occupational therapists. Thus far, the available CVI screening tools have focused on screening visual dysfunction, and no validated CVI screening tool is yet available to screen children with CP to identify the possible contribution of CVI on motor impairment.<sup>7,8,9,10</sup> Paediatric physical therapists and occupational therapists could benefit from having a CVI motor screening tool at their disposal in order to determine the extent to which CVI contributes to delays in motor disabilities in children with CP. Therefore, it is important to screen all children with CP, GMFCS levels I-V by using CVI-MQs as an additional tool to identify at-risk children with CP for the probability of having CVI. The final objectives of this thesis were to develop two Cerebral Visual Impairment Motor Questionnaires (CVI-MQs) for children with CP to describe their face validity and usability and to determine their sensitivity and specificity to detect a possible presence of CVI in children with CP. Therefore, the first initial versions of the two CVI-MQs were developed based on literature. The Delphi method was then used among two groups of experts, one familiar with CVI, in order to gain consensus about face validity and usability. The sensitivity and specificity of the CVI-MQs were subsequently assessed in 82 children with CP with and without CVI. Both questionnaires indicated very good face validity and good usability for practical use. The CVI-MQs had excellent sensitivity and specificity. The CVI-MQs are able to identify at-risk children with CP for the probability of having CVI. The development of two CVI-MQs for children with CP allow professionals working with children with CP to detect CVI in an early stage. This is important for these children as

the visual impairment is often undetected in children with CP. A lack of recognition can be problematic for a child with CVI whose inaccurate visual guidance of movement, for example, may be misinterpreted as clumsiness.<sup>11</sup> Meanwhile, the child may be doing its best, yet is continuously criticized. The outcome can be disheartening for a child, leading to low self-esteem and a sense of being misunderstood.<sup>11</sup> With the CVI-MQs, the paediatric physical therapists and occupational therapists who are often the first professionals to investigate and treat children with CP at the level of motor functioning are able to identify warning signals (higher visual risk factor) for CVI when screening children with CP. Professionals can review the impact of CVI on the observed motor behaviour and ensure the identification of signs and symptoms of CVI in children with CP. Consequently, children suspected of CVI should be referred for full assessment and diagnosis by an ophthalmologist and paediatric neurologist in order to determine the presence of ocular visual impairment by the child with CP and to identify and characterize the disorder, its cause, and effective strategies for its treatment.

In conclusion, it is recommended to implement both the adapted PEDI-NL and GMFM-88 as the CVI-MQs in daily practice for children with CP and CVI.

### CVI diagnosis

There are many variations in the manifestation of CVI as well as in the cause. Additionally, definitions of CVI vary between research groups and generally accepted diagnostic criteria are still inadequate.<sup>12,13</sup> Defining features of CVI have been described across different levels of human functioning including anatomical, functional, and behavioural levels. Currently, no agreement exists in terms of the use of cerebral imaging measures, tests to assess (cerebral) visual functioning, or the use of behavioural screening questionnaires to diagnose CVI.<sup>13</sup>

However, in the event of a CP diagnosis, especially for children with GMFCS IV-V, it is almost impossible to make a distinction between the different affected pathways because almost all brain areas are affected. Therefore, for those children with CP, it is not relevant to use the distinction between the ventral and dorsal stream. For children with CP and CVI, the motor impairment caused from CP will interfere with

impairment from CVI resulting in new phenomena which could be different from isolated CP or CVI. For example, reflexes in children with CP such as the Asymmetric Tonic Neck Reflex (ATNR) could have a greater effect on looking and reaching at the same time. The presence of CVI could result in the same behaviour as an ATNR reflex, specifically, after locating an object, looking away from it, and thereafter reaching to grasp that object. Therefore, the major challenge is to develop a set of diagnostic instruments for professionals working with children with CP and CVI. Also, there is a need to advance the diagnosis of CVI in children with CP based on quantitative parameters.

Due to the fact that there is no linear relationship between the impairment of body functions and structures, activities, and participation, it is important to use the ICF-CY (International Classification of Functioning, Disability and Health, Child & Youth version) as a tool to establish this diagnosis in children with CP, especially at the level of both activity and participation. Furthermore, professionals from all disciplines must be involved to establish a CVI diagnosis. The screening tools for detecting CVI in children with CP also should be focused at the level of functional approach and both activity and participation components of the ICF-CY.<sup>14</sup> Despite the fact that it is important to be aware of this information, the focus of our studies were at the level of both activity and participation components of the ICF-CY.<sup>14</sup>

### Consequences of CVI and assessment

The presence of CVI could result in difficulties of being able to visual locate caregivers and difficulty knowing whether they are present or absent thereby affecting the level of a child's motivation to acknowledge them. Furthermore, the child may become clumsy and become easily distressed in crowded environments.<sup>11</sup> When a child with CP exhibits a limitation of daily activities, slow motor processing, and performance speed, it may not only originate from a delay in motor and/or mental development but also from visual impairment. Furthermore, CVI can also cause behavioural problems in that child which need an approach from a perspective that is different than behavioural impairment. Using the CVI-MQs as an additional tool for screening children with CP to determine the presence of CVI is beneficial for helping professionals and caregivers

to better understand a child. CVI is the contributory cause of motor limitation in the daily life of that child rather than only a motor dysfunction. Professionals should use the CVI-MQs when a child with CP is able to perform a particular motor task during therapy but is not able to perform the same task during a motor assessment. Also, when a child with CP has difficulty with motor skills related to depth perception such as jumping and reaching, the use of CVI-MQs could be considered. Other reasons to employ the CVI-MQs could be that a child does not react toward a sound in the majority of instances; the child has difficulties letting go of the reference point such as contact with the floor or the bed in its environment; and the child has a common behaviour of "freezing" in response to interesting stimuli.<sup>15</sup> Using these validated CVI-MQs affords an opportunity to quickly obtain information of the risk of the presence of CVI for a child with CP. Furthermore, it can help paediatric physical therapists and occupational therapists to assess children with CP by using these screening tools when professionals want to ensure that the current impairments of a child with CP are perhaps also caused from the presence of CVI. It also helps to achieve a realistic impression of the capabilities of a child with CP and CVI. Presuming of the presence of CVI as a result of a positive score on the CVI-MQs could be the initial step toward an early diagnosis for a child with CP. Also, in the event of an absence of warning signals, it prevents the unnecessary comprehensive testing of children. It is also cost and time efficient. Therefore, the use of these CVI-MOs for children with CP is relevant and warranted. In addition, centres of expertise for blind and visually impaired individuals and allied healthcare practices could use the CVI-MOs for children with CP as a part of wider investigation into CVI. Finally, it helps professionals working in rehabilitation centres to identify children with CP who are at risk for the probability of having CVI.

During data collection of children with CVI, it was not always recorded in medical files which aspects of CVI were present in a child with CVI. Therefore, the centres of expertise for blind and visually impaired people are advised to develop a standard procedure for screening and recording information of children with CP and CVI. This information must include the types of CVI that are present in a child with CP. Furthermore,

it is important to explain this information to those professionals working in the rehabilitation centres in order to implement this advice during the treatment of a child with CP and CVI. The adjusted treatment for children with CP and CVI facilitate self-determination for these children and help them increase independence in daily skills. Such an intervention requires a team approach with CVI experts who work together with the experts from rehabilitation centres. Moreover, it is important to support and educate the professionals working at rehabilitation centres on how to implement knowledge on CVI in their approach for children with CP. Furthermore, factors to consider that affect visual presentation during a motor activity vary with the need of each child with CP and CVI and include the size, contrast, color, and arrangement of materials.<sup>11</sup> In addition to these, movement has also been determined to attract and maintain attention for children with CP and CVI.<sup>16</sup> It is obvious that the contribution of the parents and caregivers is the most important component of comprehensive intervention for these children.

The impact of CVI on the daily life of a child with CP could result in a delay of motor development and a greater level of dependency. It is not only important to be aware of ocular visual impairment, but also recommended to investigate the possible presence or absence of CVI in children with CP. Therefore, to meet the needs of these children, it is very important that both researchers and education centres for professionals integrate the knowledge of CVI with CP during the research studies on children with CP. It prevents a presence of bias in future studies on CP. For education of health care professionals, it is also recommended to develop special modules for children with CP and CVI which include the knowledge on CVI in children with CP and the practical implication for those children at the level of gross motor function, functional, skills and caregivers.

### Future challenges

One of challenges is that the adapted PEDI-NL and GMFM-88 be implemented in the educational program for paediatric physical therapists and occupational therapists which could eventually result in the use of these assessment instruments in clinical practice. Hereafter, a child with CP and CVI and his or

her therapist can benefit from these adapted versions. The child is able to show its capabilities at the level of functioning, and the therapist can estimate the child with CP and CVI at the proper level.

The other challenge is to Knowledge transfer and implementation of the CVI-MQs in the rehabilitation centres. The professionals working with children with CP have an advantage when using the CVI-MQs because all of the items in both questionnaires are related to the motor functioning of a child who is familiar to the professional. In the event of a positive outcome score, this child could be referred for a full assessment and diagnosis by an ophthalmologist and a pediatrician. Furthermore, in the future, it is very important to determine the psychometric proportion of CVI-MQs in children with CP and CVI.

The last, and also the greatest, challenge is to adapt or develop an intervention program for children with CP and CVI. CVI influences a child's ability to learn and perform tasks in everyday life and should, therefore, be taken into account in therapy and intervention.<sup>17</sup> In addition, the development of a visually impaired child can be delayed especially with regard to self-initiated mobility, posture, and locomotion.<sup>17</sup> It is established that CVI has an impact on all aspects of a child's development, and children with both CP and CVI develop more slowly in the areas of self-care, mobility, and social function than children with CP and without CVI.<sup>2,18,19,20,21,22,23</sup> Due to the fact that children with CP and CVI are more limited at the level of gross motor function, functional skills, and caregiver assistance, it is important that those children meet their needs during treatment by therapists giving appropriated verbal instruction and manual support.<sup>2,18,19,20,21,22,23</sup>

Children with CP and CVI also have an extended processing time to receive and interpret information from their environment.<sup>11</sup> By providing these children with extra time to understand the content of a question, they will be able to demonstrate real ability to perform a particular task. For children with CP and CVI, it is important that the environment is predictable, the decoration of a room does not frequently change, and they are involved in the layout of their room.<sup>11,16,24,25,26,27,28</sup> This may contribute to independent functioning in their daily life.

Considering the fact that a high number of children with CP also have CVI, it is very important for paediatric



physical therapists and occupational therapists to have an effective and evidence-based intervention program that is adapted for children with both CP and CVI at their disposal. It is a fact that children with CP and CVI are different from those with CP and without CVI, therefore, it is important to develop a specific intervention program for children experiencing CP with CVI in order to improve their gross motor function, functional skills, and caregiver assistance. There is evidence of the effect of different intervention programs such as functional therapy, strength training, and condition improvement to improve mobility and self-care in children with CP.<sup>29,30</sup> Novak et al.<sup>30</sup>, Franki et al.<sup>31</sup>, Gelkop et al.<sup>32</sup> and Sakzewski et al.<sup>33</sup> concluded that intervention programs that include aspects such as goal-directed training, context-focused therapy, and home-programs are the best evidence intervention programs to improve gross motor function, functional skills, and self-care in children with CP. However, those intervention programs did not take into the account the presence of CVI and its effect on motor functioning and self-care of children with CP and, therefore, they are less suitable for children with both CP and CVI.

An intervention program must have, as a basis, the following criteria: goal-oriented, focused on activities and/or participation, task-oriented, active contributing of the child and parents in learning, discovering and finding solutions, focused on functionality instead of normality and context-specific.<sup>29</sup> On the other hand, it is important to integrate the aspects from CVI into those criteria to develop such an intervention program. Those aspects could be adapting the environment by adding color to the using aids or giving verbal and manual support (e.g., duration and phase of required manual support that is given) during the specific phase of the execution of a task. Furthermore, by teaching a particular task to a child with CP and CVI, it important to begin with comprehensive hands-on training of the entire task and, when the child is familiar with the task, proceed into hands-off training of the same task.

Early intervention in a visually impaired child is stressed, and treatment of sensory input impairments should begin as early as possible in a positive emotional setting that enhances the child's motivation and relationship with caregivers.<sup>34,35</sup> Such an intervention program needs to help a child to increase its awareness of visual stimuli, improve visual attention and teach

basic visual skills as well implement compensatory strategies that are all integrated into the activities of daily life.<sup>9</sup> It is not only important to develop or adapt an intervention program for children with CP and CVI but also to ensure the implementation of it. To achieve such goals established for those children, there are three intervention aspects: 1) education of all caregivers and usual school staff about the child's visual functioning; 2) application of compensatory strategies; and 3) regular sessions of direct teaching by the caregivers and school staff.<sup>9</sup> The centres of expertise for blind and visually impaired people have significant responsibility not only by testing a child at the level of visual functioning and providing instruction and advice but also monitoring this child and being proactive. Implementing advice in the daily life of a child with CVI is a continuous process of investing in the child and its environment, and these need to be warranted by the centres of expertise for blind and visually impaired people.

In general, there are three recommendations which can be made to guide an intervention that will facilitate the development of children with CVI. First, it is critical that early identification of CVI be a focus of pediatricians and other early interventionists. Second, an intervention should focus on the use of integrated sensory information. Lastly, the intervention should be family focused.<sup>36</sup>

In the future, it is recommended to add a section for children with visual impairment into the "Guidelines for the diagnosis and treatment of children with Spastic Cerebral Palsy".<sup>29</sup> This section consists of information on CVI and OVI related to CP at the level of ICF that can support professionals' efforts to use the knowledge of visual impairments on children with CP.

### Study limitations

In the studies in this thesis, the diagnosis of CVI was determined based on the results of ophthalmological and psychological/neuropsychological assessments and on the assessment data reported by a developmental coach specialized in working with children with visual impairments. However, we did not select specific subtypes of CVI because the additional information in the medical files of which type of CVI the child was experiencing was often incomplete. As a consequence, we were not able to determine the differences between the types of CVI. This may be a limitation because it is



not clear whether the different types of CVI contributed to those studies and affected the results on the adapted PEDI-NL, GMFM-88, and CVI-MQs. However, there are several issues such as environmental and personal factors which may contribute to the execution of a motor activity and the content of the adapted PEDI-NL, GMFM-88 and CVI-MQs consist of various items which could represent all types of CVI within them. Therefore, these measurements are appropriate to use for children with various types of CVI.

In addition, brain damage resulting in CP affects several areas such as motor and visual functioning which makes it difficult to distinguish damage from various areas. In the study of the adapted PEDI-NL, the adapted GMFM-88, and CVI-MQs, we included participants with different types of CP in various degrees of severity who might have different profiles of motor functioning. Most of the participants (96%) were children with spastic CP. The studies on original PEDI-NL and GMFM-88 have demonstrated that these instruments were developed for all types of CP.<sup>6,37,38,39,40</sup> Despite the fact that most of participants were children with spastic CP, and in accordance with other studies<sup>6,15,16,17,18</sup>, the results of these studies could also be used for children with other types of CP such as dyskinetic CP and ataxic CP.

### Concluding remarks

Professionals working in rehabilitation centres must be aware of the presence of CVI in children with CP. Due to the fact that CVI results in delays of motor development and a greater level of dependency, it is important to screen children with CP and, if needed, to refer to centres of expertise for blind and visually impaired people. In the event of the presence of CVI in a child with CP, the professionals and caregivers must adjust their approach to help the child achieve an increased level of independency. Also, the knowledge about the presence of CVI in the child with CP contributes to better estimating of functioning level.

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